Hello Danish Psychologists

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Weill Cornell Medicine
Conflict of interest

- I receive royalties from diagnostic instruments, including the ADOS, ADI–R, and SCQ.

- I have research funding from NIH, DoD, Clinical Research Associates and the Simons Foundation.
Outline

- Morning

- Early diagnosis and baby siblings
- Longitudinal studies (very early and 2 to 24)

- Afternoon

- DSM 5
- Challenges for autism research and clinical work
Baby siblings studies

- Have shown higher prevalence of autism in siblings than expected (10 – 20%)
- Have NOT found a higher prevalence of children with language disorders by age three
- HAVE found a higher prevalence of children with all kinds of different social delays and limitations, though not ASD up to age 3
- Have NOT found any predictors of which siblings will have autism on an individual basis though there are group differences
- Still much controversy about when differences are apparent in those who will have ASD
Where does this leave us?

- Many interesting hints about what is different
  - Face-processing
  - Motor skills
  - Frequency and variability of babbling

- But practical implications all have to do with trajectories and rate of change
- Need for monitoring
never asd n=30 sometime asd n=48

Class 1: severe persistent 21% n=16
Class 2: worsening 21% n=16
Class 3: improving 19% n=15
Class 4: non-spect. 40% n=31
Trajectories of Clinician Certainty Ratings

Class 1: severe persistent 21% n=16
Class 2: worsening 21% n=16
Class 3: improving 19% n=15
Class 4: non-spect. 40% n=31
CSS 12–36 mos
4 groups

Age (months)

Group Percents  

- 24.0  
- 27.7  
- 23.7  
- 24.6
Interactions of Age and Diagnosis: Improving Trajectories on the ADOS -T (Lord et al, 2012)
Worsening Trajectories
Behaviors with more subtle changes in ASD

Response to Name

Level of Engagement

Amount of Overtures to Examiner and to Parent

Shared Enjoyment
Summary

Worsening of social directedness and communication is common during second year of life in ASD. Usually it occurs after some skills have plateaued or in presence of other nonspecific delays as well as while some skills are improving. More marked regressions do occur but are quite rare and often follow delays as well.
How to “capture” on one variable, at least three dimensions (early delays, loss and duration of loss) that vary at least somewhat independently? Biological models?
Longitudinal Study: 213 children referred for possible autism at 2 followed over time (now 23-25 yrs) (Lord et al, 2009).

### ASD Participants with 9 Year-Old Data

<table>
<thead>
<tr>
<th>Race (B/W) (%)</th>
<th>Gender (M/F) (%)</th>
<th>Mean Age in Mos. at First Test (SD)</th>
<th>Mean Age in Mos. at Last Test (SD)</th>
<th>Mean VIQ Age 9 (SD)</th>
<th>Mean NVIQ Age 9 (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N. Carolina</strong></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>n=102</td>
<td>39/58</td>
<td>28.7 (4.8)</td>
<td>122.0 (8.3)</td>
<td>52.4 (39.3)</td>
<td>67.2 (23.6)</td>
</tr>
<tr>
<td><strong>Chicago</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=68</td>
<td>8/86</td>
<td>29.3 (5.6)</td>
<td>98.2 (10.9)</td>
<td>55.6 (37.6)</td>
<td>74.3 (18.1)</td>
</tr>
</tbody>
</table>
Figure 1. ASEBA Anxiety subscale scores by diagnosis and gender

Figure 2. ASEBA Depressive subscale scores by diagnosis and gender
Trajectory Classes from age 2 to 12 (Gotham et al. 2012)
Modeled with Risk Variables (VIQ, NVIQ, Gender, Race)
What can we learn from the longitudinal study relevant to early identification?
Two DLS Trajectory Groups

High=34% (n=49)
Low=66% (n=96)

T2 predictors
NVMA (OR=1.29)
Soc-Com (OR=0.88)

20+hrs parent tx
(OR=5.40)

DLS AE=13.69y
DLS AE=5.01y

Low < High at all time points; p<.05

Bal et al., 2015
Low-DLS group is more impaired in multiple domains

<table>
<thead>
<tr>
<th></th>
<th>Low n=49</th>
<th>High N=36</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>18.94 (1.04)</td>
<td>19.28 (1.24)</td>
</tr>
<tr>
<td>DLS Age</td>
<td>5.56 (2.31)</td>
<td>13.92 (3.22)</td>
</tr>
<tr>
<td>NVIQ</td>
<td>28.00 (19.18)</td>
<td>90.82 (25.95)</td>
</tr>
<tr>
<td>RecLang Age</td>
<td>4.02 (3.58)</td>
<td>10.67 (5.61)</td>
</tr>
<tr>
<td>ExpLang Age</td>
<td>2.35 (1.97)</td>
<td>12.15 (7.46)</td>
</tr>
<tr>
<td>Soc+Comm</td>
<td>19.71 (5.92)</td>
<td>9.00 (5.15)</td>
</tr>
<tr>
<td>RRB</td>
<td>4.53 (2.3)</td>
<td>3.56 (2.7)</td>
</tr>
</tbody>
</table>

Bal et al., 2015
Group overlap in mild-to-borderline range of cognitive impairment

Low
n=96

High
n=49

Nonverbal IQ vs. Age
## Indicators of Current Functioning for Youths with IQ > 70

### Sample Characteristics

<table>
<thead>
<tr>
<th></th>
<th>More Able ASD</th>
<th>VPO</th>
<th>Effect Size</th>
<th>(Unadjusted) P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=24</td>
<td>N=8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M (S.D.)</td>
<td>M (S.D.)</td>
<td>Eta^2</td>
<td></td>
</tr>
<tr>
<td>Verbal IQ</td>
<td>103 (17.69)</td>
<td>111 (14.40)</td>
<td>.04</td>
<td>.26</td>
</tr>
<tr>
<td>Adaptive Skills^2</td>
<td>78 (12.23)</td>
<td>101 (13.94)</td>
<td>.40</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Behavior/Mood Problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irritability^3</td>
<td>6.2 (7.26)</td>
<td>.25 (.71)</td>
<td>.16</td>
<td>.03</td>
</tr>
<tr>
<td>Hyperactivity^3</td>
<td>6.8 (7.59)</td>
<td>.38 (.52)</td>
<td>.14</td>
<td>.03</td>
</tr>
<tr>
<td>Depression^4</td>
<td>26 (8.95)</td>
<td>16 (2.03)</td>
<td>.25</td>
<td>.004*</td>
</tr>
</tbody>
</table>

### Phi

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>% Living Independently</td>
<td>13</td>
<td>63</td>
</tr>
<tr>
<td>% in College</td>
<td>71</td>
<td>88</td>
</tr>
<tr>
<td>% Employed</td>
<td>25</td>
<td>63</td>
</tr>
<tr>
<td>% Psychotropic Meds</td>
<td>38</td>
<td>13</td>
</tr>
</tbody>
</table>

1. Asterisks indicate that alpha remained significant at p < .05 after adjustment for multiple comparisons.
2. Standard scores are from the Vineland Adaptive Behaviors Scales II.
# Table 5

## Group Differences in Early Childhood for More Able Youths

<table>
<thead>
<tr>
<th>Measure</th>
<th>More Able ASD</th>
<th>VPO</th>
<th>Effect Size</th>
<th>(Unadjusted) P value&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=24</td>
<td>N=8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M (S.D.)</td>
<td>M (S.D.)</td>
<td>Eta&lt;sup&gt;2&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td><strong>Repetitive Behaviors&lt;sup&gt;2&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 2</td>
<td>2.5 (1.72)</td>
<td>3.3 (3.02)</td>
<td>.03</td>
<td>.34</td>
</tr>
<tr>
<td>Change 2 to 3</td>
<td>.83 (2.19)</td>
<td>-1.7 (2.73)</td>
<td>.19</td>
<td>.01*</td>
</tr>
<tr>
<td><strong>Social Delays&lt;sup&gt;2&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 2</td>
<td>14 (4.94)</td>
<td>12 (3.67)</td>
<td>.03</td>
<td>.37</td>
</tr>
<tr>
<td>Change 2 to 3</td>
<td>-3.6 (5.22)</td>
<td>-4.4 (4.16)</td>
<td>.01</td>
<td>.68</td>
</tr>
<tr>
<td><strong>Daily Living Skills&lt;sup&gt;3&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 2</td>
<td>73 (9.96)</td>
<td>70 (4.71)</td>
<td>.03</td>
<td>.33</td>
</tr>
<tr>
<td>Change 2 to 3</td>
<td>-2.7 (10.62)</td>
<td>-.63 (8.22)</td>
<td>.01</td>
<td>.61</td>
</tr>
<tr>
<td><strong>% Yes</strong></td>
<td></td>
<td></td>
<td>Phi</td>
<td></td>
</tr>
<tr>
<td>Hyperactivity&lt;sup&gt;4&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 3</td>
<td>50</td>
<td>0</td>
<td>-.45</td>
<td>.01*</td>
</tr>
<tr>
<td>&gt; 20 Hrs. Treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 3</td>
<td>54</td>
<td>100</td>
<td>.42</td>
<td>.02*</td>
</tr>
</tbody>
</table>

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1. Asterisks indicate that alpha remained significant at p < .05 after adjustment for multiple comparisons.
2. Scores represent algorithm totals from the ADOS.
3. Standard scores from the Vineland II.
4. Single item taken from the ADI-R.
Trajectories of Vineland Communication Ages

- Class 1: 31%
- Class 2: 14%
- Class 3: 8%
- Class 4: 12%
- Class 5: 8%
- Class 6: 21%
- Class 7: 6%

age_years

Age at data-point
Verbal IQ by Group

Mean

LA ASD  MA ASD  VPO

Age 2  Age 19
Changes from Age 2 to 3 by IQ

**Verbal IQ**

- **Group**: MA ASD, OO, LA

**Adaptive Skills**

- **Group**: MA ASD, OO, LA ASD

**Social Delays**

- **Group**: MA ASD, OO, LA

**RRBs**

- **Group**: MA ASD, OO, LA ASD
Three classes of trajectories based on change of RSM

Richler, et al., 2010
Three classes based on change in insistence on Sameness
<table>
<thead>
<tr>
<th>Early</th>
<th>From 2 to 19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall variability 12 – 30 months in core features</td>
<td>Gradual social and adaptive improvements that start early but persist to 19 in best outcome</td>
</tr>
<tr>
<td>Some social skills go up while others go down</td>
<td>Steady improvements in basic social skills even with ID and autism to 19</td>
</tr>
<tr>
<td>Early plateaus and losses</td>
<td>Increased social withdrawal in some verbal adolescents</td>
</tr>
<tr>
<td>Rapid improvement in language from 2 to 3</td>
<td>Increased depression and anxiety in girls in adult</td>
</tr>
<tr>
<td>◦ Necessary, not sufficient</td>
<td></td>
</tr>
<tr>
<td>◦ “Late bloomers”</td>
<td></td>
</tr>
</tbody>
</table>
Changing the social course of ASD...

Early core deficits may lead to a cascading effect on neurodevelopment that arises from impoverished social interaction.

(Mundy & Burnette, 2005)

Underscores the importance of early interventions
One pathway was associated with a combination of behavior problems, history of repetitive behaviors and aggression, negative affect and poor adaptive behaviors. We need to know more about how hyperactivity and attention deficits contribute to this pattern.

Another pathway was associated with depressive symptoms in adolescence. When this was associated with anxiety and strong resistance to change, all scores were elevated even more. The suggestion of sex differences in this pattern is very interesting.

We need to build models that include strengths; Many more adolescents showed improvements than worsening
Afternoon

- Slides about parent-mediated training
  - PACT
  - ESI (Amy Wetherby, SCERTS)
  - JASPER (Connie Kasari)

- Quick video of home-based intervention (how fit with daycare?)
  - CADB: preschool 3 X week, 2 hours in class (ESDM)
    - hour individual speech therapy, 1 hour “push in”
  - 1 hour occupational therapy, 1 hour “push in”
  - 3 hours parent-mediated at home, 1 hour in clinic
  - 2 hours parent group (one psycho ed; 1 support)

- DSM 5 and assessment
- Challenges in research and clinical work
Different aspects or different treatments have overlapping but different effects

Caregiver factors
- Shift expectations to possible behaviors
- Relationship with the child
- Confidence and empowerment
- Dealing with behavior
- Communication
- Dealing with own fears and feelings

Child factors
- Understanding what is happening
- Ability to pay attention
- Learning of specific skills
- Communication
- People as positive
- Activity “tools”
- Tolerance of frustration/intrusion
Research tells us that a variety of intervention strategies work well with some children with ASD. 

<table>
<thead>
<tr>
<th>Traditional Behavioral/Discrete Trial</th>
<th>Contemporary Behavioral/ Naturalistic</th>
<th>Developmental/Social-Pragmatic</th>
</tr>
</thead>
</table>

*(NRC, 2001)*
Responses to EI: what does this mean for the rest of life?

- Intensive ABA: increases in IQ and language scores of 10 – 20 points.

- Brief parent-oriented and direct interventions for joint attention: changes in language, attention, IQ.

- Specific interventions (e.g., behavior plans, pausing, schedules) result in specific improvements.

- Child/parent by tx interactions; hope for toddler treatments
PACT results (Green et al., 2010)

- British national study
- Within the scope of National Health Service
- 12 week home-based parent-mediated program (SLP’s): 1 – 0.5 times a week
Parental Intervention

**PREDICTED**

- Maternal Synchrony → Child Joint Attention → ADOS Scores → Peer Interaction

**RESULTS**

- Intervention → Maternal Synchrony
- Intervention → Child Joint Attention

Characteristics of research interventions

- 12 weeks is modal time
- Some RCT’s
- Small samples
- Kids primarily verbal, higher IQ (some exceptions)
- Outcomes are often knowledge, parent reports -- some SSRS, “hosting;” friendship relationships, some playground
Different goals for different kinds of evaluations

General issues and strategies

Purposes of assessment
- Diagnosis, Cognitive and Domain-specific, Behavior issues

Age and development related issues

Using an assessment to step back and consider short-term and longer term goals (don’t think we do this enough)
Purpose of assessment

Think about it in terms of what you’re trying to accomplish:
- Get information
- Get recommendations or referrals
- Get services

Think about it in terms of the kinds of information you need
- Diagnostic
- Cognitive
- Domain –specific (language, motor etc)
- Behavior and co–morbidities

Relationship that you will continue
What can an evaluation offer you?

- The person: who has seen, in many cases, 100’s of people with ASD, and people with other kinds of difficulties

- The tests: structure of how to think about how a child or an adult thinks and remembers and organizes information and interacts and plays

- The opportunity for you to watch (does not have to be every time) – most relevant to older children and adolescents
Sources of confusion

- Billing in psychology/neuropsychology and medicine
  - For procedures when you are physically with a patient
    - Not for writing or thinking or making phone calls or scoring (unless you are charging through a private practice)

- Good assessment
  - Based on good preparation and organization – knowing what has been done before and what you’re looking for

- Besides “tickets” into services, a few individualized recommendations may make the most difference
What can you do right at the start?

- Make short lists of what you want from the assessment that you send in with any packets.
- Take them with you to all appointments (don’t count on anyone’s memory).
- Don’t be shy about taking notebooks. Don’t send long videos but take short ones with you.
- Be as polite as you can even if you’re frustrated.
- Stick up for yourself and your child and respectfully keep reiterating how you think the professional might be able to help you (without telling them what to do).
- Practitioners may have a list too (ask them) and also how they may want you to behave.
Pervasive Developmental Disorders

- Social Impairment
- Repetitive Behaviors & Restricted Interests
- Speech/Communication Deficits
- Autism
- Language Disorders
- Intellectual Disabilities
DSM 5 Committee on Neurodevelopmental Disorders

- Susan Swedo, M.D., pediatrician and chair
- Gillian Baird, M.D., developmental pediatrician
- Edwin Cook Jr, M.D., child psychiatrist
- Francesca Happe, Ph.D., developmental psychologist
- James Harris, M.D., child psychiatrist
- Water Kaufmann, M.D., neurologist
- Bryan King, M.D., child psychiatrist
- Catherine Lord, Ph.D., clinical psychologist
- Joseph Piven, M.D., child psychiatrist
- Sally Rogers, Ph.D., developmental and clinical psychologist
- Sarah Spence, M.D., child neurologist
- Rosemary Tannock, Ph.D., pediatric neuropsychologist
- Amy Wetherby, Ph.D., speech-language pathologist
- Harry Wright, M.D., child psychiatrist
DSM5 process

- Committee and chair appointed by American Psychiatric Association
- Weekly conference calls; face to face meetings about every 3 months for 4 years
- Decisions made through discussion, drafting of proposals, consensus in most cases
- Various advisors consulted, including autism self-advocates and other experts
- Drafts posted and comments reviewed
- Drafts written by individuals, reviewed by subcommittees and then full committee and DSM5 review groups
Within our committee, we had access to several large datasets predominantly of clinical referrals for ASD and research participants in ASD projects, but also some individuals with related, but non-ASD diagnoses (existing data).

Iterative analyses were run, reviewed and re-run to test alternative aspects of drafts, but in the end committee discussion preempted data.

DSM5 field trials were conducted with draft criteria; committee was given results.